Closing the Organ Gap: A Reciprocity-Based Social Contract Approach

Gil Siegal and Richard J. Bonnie

Organ transplantation remains one of modern medicine's remarkable achievements. It saves lives, improves quality of life, diminishes healthcare expenditures in end-stage renal patients, and enjoys high success rates. Yet the promise of transplantation is substantially compromised by the scarcity of organs. The gap between the number of patients on waiting lists and the number of available organs continues to grow. As of January 2006, the combined waiting list for all organs in the United States was 90,284 (64,933, 17,269, and 3,006 for kidney, liver, and heart respectively).1 Unfortunately, thousands of potential organs are lost each year, primarily due to lack of consent to donation from the deceased before death, or from the family thereafter.2 Only fifty percent of potential donors—the "conversion" rate—become actual donors. The costs attributed to organ shortage are substantial—Medicare paid over $15.5 billion in 2002 for treating patients with end-stage renal disease, who predominate on organ waiting lists.3

Although live donation is a valuable and fast-growing source for organs,4 deceased donors remain essential. The Breakthrough Collaborative,5 sponsored by the Health Resources and Services Administration (HRSA), helped organ procurement organizations (OPO) achieve a ten percent increase in deceased donors in 2004, as well as continuing progress in 2005.6 Notwithstanding these improvements, the gap between supply and demand continues to widen. Pursuant to Congressional direction,7 HRSA has requested the Institute of Medicine (IOM) to conduct a comprehensive study of "proposals and efforts to increase organ donation," including the ethical implications, feasibility and cost-effectiveness of contending approaches. While continuing efforts to improve the current system are essential, more fundamental changes will likely be needed.

Among the ideas that have been proposed to increase prospective donations, "mandated choice," endorsed in principle by the AMA in 1994,8 would require people to state their preferences regarding organ donation when performing state-mandated tasks, such as renewing drivers licenses or filing tax returns. This approach would leave the current donation-based system in place while trying to overcome impediments that prevent people who are inclined to be donors from recording their desire to do so and that tend to dissuade their families from authorizing organ removal upon death. However, a decade later, no state currently uses this approach,9 and its critics have argued that it could be counterproductive if ambivalent or even distrustful people are forced to make a decision on the record.10 Flanking the mandated choice approach on either side are proposals that depart more substantially from the existing system. On one side is a cluster of incentive-based proposals that appeal to the self-interest of potential donors rather than to their altruistic disposition— for example, providing financial incentives or giving priority on waiting lists to people who have...
declared their willingness to be donors. Despite their psychological plausibility, incentive-based approaches have been strongly resisted by many transplantation specialists and bioethicists because they would displace altruism with self-interest as the driving force in the system, and would offend the spirit, if not the letter, of the National Organ Transplantation Act (NOTA) prohibition against "valuable consideration" for organ donation.

Flanking mandated choice on the other side are approaches that give greater weight to collective concerns. Some would dispense with the need for consent altogether on the ground that the public interest in saving lives overrides the interests of either the deceased or the deceased's family in determining post-mortem disposition of the body. A number of other proposals, grouped under the heading of "presumed consent," would dispense with the need for explicit consent from the deceased or the family, assuming instead that donation is desired unless people say otherwise. In other words, this approach would shift the legislative default from non-donation to donation, converting the present "opt-in" system to an "opt-out" system. Other approaches are grounded in a communitarian perspective; a typical communitarian approach would try to preserve the principle of individual or family consent while shifting the social norm from personal altruism to a spirit of collective obligation. We present here a practical model based on a social contract that combines the best elements of these competing approaches, while building on the foundation already laid by NOTA in 1984.

First, we would promote a reformulated social understanding of the moral premise of organ donation by emphasizing reciprocity as well as altruism ("reciprocal altruism"). Everyone is a potential recipient as well as a potential donor. Even the best health insurance program that money can buy cannot provide a needed organ. The gap in organ supply can be substantially closed only if most members of society, regardless of class or race, are willing to participate. Regrettably, the reciprocal interest in an organ – a potentially powerful social and psychological instrument – has so far been overlooked in communicating with the public. Organizations and programs promoting organ donation have not expressly and persuasively drawn the connection between the chances of being a future recipient and prospective statement of willingness to donate. Even the best health insurance program that money can buy cannot provide a needed organ. The gap in organ supply can be substantially closed only if most members of society, regardless of class or race, are willing to participate.

We do not believe that focusing on mutuality requires a change in social values. Nor are we suggest-
In 2004, approximately 8,500 people were removed from organ waiting lists due to death or deterioration beyond the stage of benefit from transplant, most of whom were waiting for hearts (550 patients), livers (2,200 patients) and kidneys (4,700 patients). If the 2004 conversion rate (potential donors who become actual donors) would increase from the current fifty percent to seventy-five percent (i.e., from 7,150 to some 10,000 deceased, multiple organ donors, and assuming 1.7 kidney transplants, 0.3 heart transplants and 0.89 liver transplants per deceased donor), 900 additional hearts, 2,700 additional livers, and 5,000 additional kidneys respectively would be donated, thereby assuring that no one would die while awaiting an organ. Increasing the conversion rate to seventy-five percent might also make it possible to achieve the more ambitious aim of offsetting new additions to the waiting lists which totaled, for kidney, heart, and liver, 28,300, 2,800, and 10,600 respectively in 2004. Closing the entire gap would probably require a higher rate of conversion over time, along with efforts to increase the pool of medically appropriate deceased donors, including the numbers of donors declared dead by circulatory criteria.

Once the American public recognizes that organ procurement is a component of a system of transplantation "insurance," individuals will easily see why willingness to be an organ donor is in everyone's rational self-interest. Instead of focusing exclusively on altruistic consent to become potential donors, the underlying principle of NOTI is that aggregated present consent to donate guarantees the future availability of organs for those who need them to survive – at least to the point of preventing death while on waiting lists due to organ scarcity. Immunization, which relies on mutual protection afforded by herd immunity, is an adequate analogy.

It is important to emphasize that the term "insurance" is being used here in a colloquial sense, and not a technical legal sense. The envisioned relationship between premium (promised donation) and protection (transplantation when needed) is reciprocal in principle only, not in legal fact. For one thing, the availability of organs cannot be guaranteed for anyone, since it will always be contingent on the actual rate of donation. Also, in a firmly reciprocal system such as private ins-

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We propose a national plan of organ transplantation insurance, grounded in the expectation of reciprocal participation by the people of the United States, under which the federal government assumes responsibility for increasing the organ supply and covers, as payer of last resort, all the costs associated with transplantation. Coupling procurement and coverage is necessary to promote donation by minorities and the uninsured. The ultimate goal of the plan is to make organs available to everyone for whom, under current protocols, transplantation is medically indicated. In the short run, all that can be assured is equal access to the pool of available organs without regard to ability to pay (i.e., no "green screen") and a reasonable expectation of enough available organs to prevent anyone on the waiting list from dying due to a lack of donors.

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surance, willingness to donate and eligibility to receive organs would be linked, and declining to donate would preclude eligibility to benefit, raising the many practical and moral problems mentioned earlier. However, no country has conditioned eligibility to receive an organ on recorded consent to donate, and there is no need to take such a drastic action, as long as the necessary supply of organs can be assured without doing so.

Our present goal is to offer only an exploratory proposal rather than a detailed plan. Translating this vision into a concrete policy will require empirical research, specific decisions about financing, determining the necessary role of the national government, and choosing mechanisms of promoting donation and recording donor preferences. Furthermore, transitional provisions would be necessary because the full benefits of the plan would not be realized immediately, while costs would be incurred right away. Further, creating the plan is likely to expose a latent demand, increasing the gap rather than closing it at the outset. However, these transitional problems relate to implementation of the plan, not to its long-term feasibility.

A Federal Entitlement to Organ Transplantation Services

A federal entitlement to transplantation and post-transplantation services for all medically-indicated patients under an all-payer model, with federal payment (probably under Medicare) for patients not otherwise covered, is a morally essential and economically sensible element of NOTI. Although the United States currently lacks a national system for either the financing of or delivery of healthcare, organ transplantation is uniquely well-suited to a universal benefit with last-resort national financing. The federal Medicare program is already responsible for the overall treatment of ninety-two percent of patients with end-stage renal disease who dominate organ waiting lists, and all patients' clinical, epidemiological and cost information is assembled and monitored by the United States Renal Data System (USRDS). In the absence of universal health insurance, some might reasonably ask why organ transplantation should be privileged over so many other competing medical needs. However, costs are already being covered by Medicare for transplantation of most kidneys, and the overall procurement strategy would be incoherent if other organs were not included.

The NOTI entitlement would be cost-saving for people now receiving renal dialysis after a few years: successful kidney transplantation has been proven to save $27,000 per year beginning 2.7 and 4.9 years after live and deceased donor transplantation respectively. Although transplantation of other organs is not similarly cost-saving, its net costs would be relatively modest once arrangements have been negotiated (estimated costs for kidney, liver and heart transplantation for year one – $48,500, $117,400 and $153,500, after year one – $9,600, $19,000 and $12,700, respectively); the costs per year of life (or QALY) gained are modest. Based on a figure of $100,000 per QALY, the net benefit provided by each additional organ donor has been estimated at $1 million.

Under our plan, organ transplantation coverage would be covered by the federal government as a last resort for anyone not otherwise covered. In addition the federal government would use health insurers and health care organizations, as well as Medicare as channels for educating people about NOTI and the social contract upon which it rests. Ultimately, NOTI is designed to help increase the supply of organs and thereby to replace an illogical arrangement under which most people pay annual premiums to cover transplantation costs without any assurance that organs will be available.

A National Procurement System

The federal government must also strengthen its role in ameliorating the current scarcity of organs. NOTI is aligned with the premises of NOTA, and represents a natural progression of its underlying aims. NOTI is designed to establish a truly national system of organ procurement to complement the national system of organ allocation established by NOTA and implemented through the contract between the federal Health Resources and Services Administration (HRSA) and the United Network for Organ Sharing (UNOS). Regional coordination of organ retrieval and allocation should remain the norm, as dictated by NOTA. However, the federal government should assume greater responsibility for coordinating the system, stewarding this highly-sensitive resource on behalf of society, as it has already begun to do through HRSA support for the Breakthrough Collaborative, a series of initiatives designed to identify and disseminate practices that have succeeded in increasing conversion rates, and through proposed performance requirements for OPOs and transplant hospitals promulgated by the Center for Medicare and Medicaid Services (CMS). (It should be emphasized that the government would not hold property interests in the organs or utilize them for other purposes, such as research. Our proposal is limited to for-treatment organ donation.)

Specifically, under NOTI, Congress would preempt the current state laws governing organ donation, prescribe a national legal approach to consent, and direct the Secretary of the DHHS to promulgate regulations and policies governing consent and the authority to
retrieve organs. The DHHS would maintain and moni-
tor central registries of explicit individual donor status
(both consenting and declining individuals) accessed
by all means of telecommunication, and would man-
date verification of the deceased’s consent status prior
to organ procurement.24

Consent and Refusal: A Strategy of
“Expected Donation”
The goal of increasing life-saving transplantation
under NOTI can be achieved only by increasing the size
of the participating donor pool. Once a critical mass
of potential donors has been achieved, availability of
organs can be secured to a much higher probability – at
least to the point of preventing death of people on wait-
ing lists due to organ scarcity.25 Yet if the number of
consenting individuals falls below what is statistically
needed, the promised protection might be imperiled.

The present default has the unfortunate side effect of forcing most individuals
into the position of being what economists call “free riders” – they are eligible
to receive an organ even though they have not agreed to be donors.

The Breakthrough Collaborative is pursuing a variety
of steps to increase the rate of donation, and those ef-
forts, if successful, must be sustained. A key question,
however, is whether a more radical reform is needed,
such as use of financial incentives or a shift of the legal
default from non-donation (opt-in) to donation (opt-
out). The approach most consistent with the logic of
NOTI is a shift in the default.

Setting the Default
Currently, most people who die under circumstances
that make them potentially suitable donors have not
expressed their wishes about donation one way or the
other. Less than thirty percent hold donor cards, and
the percentage of adults in state registries ranges be-
tween one and fifty-six.26 Under the current legal re-
gime, a person is not regarded as an eligible donor in
the absence of his or her explicit consent or the consent
of a family member after death. In other words, the
current default for organ donation is non-participa-
tion, and organs may be retrieved only with expressed
consent.

It is well-known that setting a default is a key ele-
ment of formulating many public policies and has a
significant impact on participation rates. Psychological
inertia plays a key role. Making a life-changing decision
often entails educational efforts and causes inconve-
nience and stress, whereas simply accepting a pre-de-
termined default appears to be effortless. In addition,
people might believe that policymakers have selected
the default to signal a preferred course of action.27 In
the context of organ procurement, there is good rea-
son to believe that donation rates are significantly af-
fected by the personal costs of deciding whether to
be a donor, and that the opt-in arrangement fails to
signal the collective importance of becoming a donor.
Indeed, rates of donation tend to be lower in countries
requiring an affirmative expression of consent (e.g.,
the UK, Germany, the Netherlands) than in countries
presuming it instead (e.g., Austria, Belgium, Finland,
France, Spain).28

Research and public opinion polls strongly suggest
that the low rate of documented consent for organ
donation in the United States is not necessarily an
indication of genuine unwillingness to donate upon
one’s death.29 Instead, it can be largely explained by

Although requiring explicit consent might be a sen-
sible default in a legal system grounded solely in altrui-
sm, presumed participation is the logical default in a
system predicated on a norm of reciprocity. Indeed, the
present default has the unfortunate side effect of forcing
most individuals into the position of being what econo-
mists call “free riders” – they are eligible to receive an
organ even though they have not agreed to be donors.30
While free-riding is not unique to transplantation (it is
permitted in mandatory immunization programs and
is widespread in the voluntary context of blood transfusion), its magnitude in this context (contributing to
unnecessary death and suffering of tens of thousands of patients) calls for a more robust response. Changing
the default in this context by presuming consent would also have the advantage of signaling that policymakers
(acting on behalf of society) are not neutral on whether people donate, as the present rule seems to suggest.
Presumed consent makes sense not only because most people actually want to donate, but also because the
norm of reciprocity implies that they ought to do so (in the absence of religious or spiritual objections).

Presumed consent proposals are sometimes criticized on the ground that people may lack
genuine opportunities to decline participation.\(^3\) It is possible, however, to link frequent reminders of the
legal principle that donation represents the default with genuine opportunities to decline to participate. For individuals who have private health insurance (including the great majority who enroll in plans through their employers), an annual notice from the insurer or health plan could serve as a yearly reminder of each individual's consenting status and provide an opportunity to record one's wishes. The opportunity to opt out could also be included in annual mailings to Medicare and Medicaid recipients. These mechanisms use appropriate instruments to communicate information about the choices required under NOTI, and should erase the concern that organs will be recovered contrary to real-but-unstated wishes. As for persons without health insurance, targeted public education campaigns and notices attached to other state-mandated activities, for example applying for or renewing a driver's license, can also assure ample opportunities to opt-out.

Long term, we believe that a shift to a legal rule of presumed consent or presumed donation is a morally
sound solution to the problem of the inertia and the "sticky default." However, it would be premature to
take the legal rule until the rest of the NOTI plan has been implemented – for example, until educational
measures will be required to counteract these fears as it will be essential to assure that the benefits of NOTI accrue equally to all social groups. These measures may include, among others, focused dialogue with communities and their leaders, multi-ethnic participation on death-determining teams, close scrutiny of allocation decisions, and continuing efforts to monitor and eliminate disparities.

A second reason for an incremental approach is that, in this context, a change in social norms must pre-
cede a change in the legal rule, rather than vice versa. The critical issue under a presumed consent system is
what happens when no objection has been recorded by the deceased. Under a strong version of the presumed
consent rule, the willingness of the deceased to donate would be presumed and the family would not even be consulted. Under a weaker version, the family would be consulted for the limited purpose of ascer-
taining whether they know of any unrecorded objection by the deceased. Family consent, per se, would not be required. In practice, however, organ procurement personnel are reluctant to proceed without family con-
sent, even in countries with presumed consent laws.\(^5\)

Any materials for recording donor status should encourage people to think about their reasons for
donating or declining to do so, and if they do decline, about their willingness to receive an organ.

consent might actually reduce the level of donation rather than increasing it if the change were interpreted
not as an act of solidarity but as an official "grab" for organs from the uneducated, vulnerable and dispos-
sessed (e.g., people with cognitive impairments).

It is especially important to address the concerns of people who are distrustful of the health care system
and the motives of people who seek consent for organ retrieval.\(^3\) For example, some potential donors, espe-
cially minorities, may be fearful that life-sustaining treatment may be selectively withheld from minority
patients or that death may be hastily declared in order
to harvest organs.\(^3\) Unless this problem is successfuly addressed, NOTI's central aim (guaranteeing an
adequate organ supply) would be thwarted. Special measures will be required to counteract these fears as
it will be essential to assure that the benefits of NOTI accrue equally to all social groups. These measures may
include, among others, focused dialogue with communities and their leaders, multi-ethnic participation
on death-determining teams, close scrutiny of allocation decisions, and continuing efforts to monitor and
eliminate disparities.

As a result, there is often little operational difference between the opt-in system and the opt-out system. Indeed, the variance between law and practice is acutely evident in the frequent U.S. practice of acceding to family refusals even in cases in which the deceased has explicitly consented to donation.\(^5\) Legally, the Uniform Anatomical Gift Act, adopted in most states as well as
most states' laws ("First-Person Consent") have already explicitly negated the possibility of family overruling the deceased's consent. However, most OPOs will yield if a family refuses to abide by it. This concern was recently addressed by the HRSA sponsored Collaborative Best Practice Report.

In sum, the immediate challenge is to change the social norm so that it favors donation. We refer to the desired norm as "expected donation." If this is successfully accomplished, the legal rule might eventually be changed to ratify and reinforce the emerging norm as long as there is no significant risk of destabilizing the current system. In the meantime, we recommend gradual steps in the direction of instilling an expectation that everyone is a potential donor while allowing ample opportunity for individuals with religious or spiritual objections to decline. By emphasizing expectations of reciprocity and mutual self-interest, messages to potential donors and interactions with family members can create a strong expectation of donation, thereby surmounting the psychological barriers to consent that have weakened the current legal regime.

**Increasing Expressions of Willingness to Donate**

Efforts to encourage formal donations and to record them in accessible registries should be intensified. In addition, people should be encouraged to express their willingness to donate verbally so that their families are aware of their wishes. Messages along this line can be included in educational materials and media spots relating to advance directives for end-of-life care.

Any materials for recording donor status should encourage people to think about their reasons for donating or declining to do so, and if they do decline, about their willingness to receive an organ. Any discrepancy between the willingness to receive an organ while refusing to donate will then be well-illuminated. We hope that such an approach would diminish unintentional free-riding while honoring the wishes of those who genuinely wish to forgo participation in the organ transplantation system altogether or only as a donor.

In sum, the process of recording one's preferences, one way or the other, should be regarded as an opportunity for promoting genuinely informed decisions.

**Making Decisions to Decline Explicit**

We acknowledge that some people have spiritual or religious objections to dismemberment of the body. Exemption for religious or philosophical objections are allowed in most otherwise mandatory vaccination laws, and it is necessary to accommodate them in the present context as well. Although an opt-out registry is not strictly necessary under an explicit consent system, it would advance the effort to instill a norm of "expected donation." As educational materials and media campaigns draw attention to the desirability of donation, people who wish to deviate from the expected path should be encouraged to make their preference explicit so that it is not overlooked after death.

The advantages of respecting refusals should be openly acknowledged. The sincere tenacity of objectors may provide valuable information needed to improve the process of procurement and distribution of organs: for example, it might expose conceived flaws in practices relating to determining and declaring the time of death, increase respect for human remains, allow conflicts of interest to be avoided, and assure fair allocation of organs to minorities and the underprivileged. Under the current system, such issues may be overlooked and therefore may be inadequately addressed. With no "watchdog," systems tend to go astray.

**The Role of Families**

Families will remain an important element in any procurement scheme. The current practice accords them a de-facto veto over organ donation. However, a strategy of "expected donation" would put them in a different position. By emphasizing the role of reciprocity in organ procurement, we hope to create an understanding that most people who do not express an objection implicitly consent to participation. Accordingly, the interaction with the family should be framed as an expected ratification of the likely wish of the deceased to donate. The OPO personnel should notify them of the declaration of death, the organs' suitability for life-saving donation, and the assumption that they will be made available to save the lives of others unless they know that the deceased would have had spiritual or religious objections. In the context of a properly designed public education campaign, the great majority of families can be expected to acquiesce. In the case of objecting families, however, the body should be left intact.

**Conclusion**

Implementation of the ambitious goals of the NOTA has been plagued by a growing gap between the number of organs needed for transplant and the number of organs available. We believe that the chronic organ shortage can be ameliorated by modifying the present approach to one that couples altruism with an emphasis on reciprocity and fairness.

Under the proposed model of transplantation "insurance," the community and all its members are provided concrete benefits (guaranteed coverage of the costs of organ transplantation, equal opportunity to receive an organ, and a reasonable prospect of receiving an organ when needed to prevent death) in return for general ac-
ceptance of the reciprocal obligation to donate. While this approach emphasizes collective engagement, it also accords respect to the wishes of those who do not want to be donors.

From a societal perspective, NOTI would increase the number of organs while potentially reducing the overall costs of treating end-stage organ diseases. The economic gains from kidney transplantation are established, and the benefits of transplanting other organs could offset most of the expenses of these procedures even without quantifying the value of added years of life. From an individual perspective, NOTI offers to all the security of knowing that an organ will be available for transplantation if it is needed to save one’s life as long as a spirit of reciprocal obligation prevails. NOTI merits serious consideration as a morally sound and practical solution to the current organ shortage.

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4. Waiting list data, supra note 1.
6. Id.
17. See supra note 1.
22. See Mendeloff, et al., supra note 19.
29. See supra note 8; Johnson, supra note 27; Sunstein, supra note 27.
30. Id.
35. Id.
37. See Wendler, supra note 36.
40. See supra note 5.
42. See Siminoff, supra note 34; Capron, supra note 39.
43. See Mendeloff, supra note 19.